Living in a nursing home : a phenomenological study exploring residents loneliness and other feelings

Living in a nursing home: a phenomenological study exploring residents' loneliness and other feelings

Abstract

Background: Loneliness is suggested to be one of the most prominent feelings nursing home residents are struggling with, and is related to various negative health outcomes and impaired quality of life. While there has been some research on social predictors and the impact of depression and loneliness on social relationships in nursing home residents, there has been very little qualitative research in investigating their own perception of such feelings.

Objective: To explore general feelings among nursing home residents, with a specific interest in loneliness in order to develop strategies for support and relief.

Method: This phenomenological study used an interview guide with open-ended questions to ensure focused in-depth data collection. Data were obtained through face-to-face interviews (n=11). Interpretative Phenomenological Analysis was used for data analyses.

Results: Loneliness is more than being alone among others. The residents' unfulfilled need for meaningful relationships plays a crucial role in feelings of loneliness. Losing their self-determination due to institutionalisation was strongly related to loneliness and caused strong emotions, such as grief.

Conclusion: It is vital that health care professionals are aware of these feelings and pay more attention to resident preferences while developing (individualized) interventions to prevent loneliness.

Key words: autonomy; loneliness; grief; existential; nursing home; phenomenological study

Word count: 4435

Introduction

Studies suggested that loneliness is one of the most prominent feelings among older people residing in nursing homes (NHs): loneliness is experienced by 55% of older people living in institutional settings (1). Generally, loneliness is defined as a subjective, unpleasant and distressing feeling resulting from the perception of a discrepancy between one's desired and achieved levels of social relations (2). Loneliness is the social isolation one experiences when one's social needs are not being met by the quantity nor the quality of one's social relationships (3). Emotional, social and existential dimensions of loneliness have been suggested (4-6). While emotional loneliness is due to the absence of an intimate relationship or a close emotional bond, social loneliness is related to a lack of meaningful relationships with a larger group of people and might result in feeling socially disconnected from others (4, 5). Existential loneliness is defined as 'a universal human characteristic, inborn in all persons and not related to object loss or lack of intimate relationships' (4-6). However, loneliness and its dimensions are perceived and defined differently depending on their context (e.g. in a nursing vs philosophical context) (6). As NH residents are not alone, surrounded by their fellow-residents and health care professionals, emotional and existential dimensions may have a central position in NH residents' feelings of loneliness. However, research investigating residents' own perception of loneliness is scarce.

Many factors can cause residents to feel lonely. Aging comes with experiencing loss. Due to death of family and friends, the social environment decreases (7). Widowhood, declining health, impaired mobility and loss of vision and hearing can reduce meaningful engagement with others, and put older adults at risk of loneliness (8). When older adults move to a NH, research suggests they lose their social environment and the related memories (1, 7, 9).

Health care professionals need to understand and be aware of feelings of loneliness as it has a negative influence on general health, life satisfaction and quality of life (1, 10, 11). Loneliness has been related to an increased risk of coronary heart disease, high blood pressure, sleeping disorders, pain and anxiety. Furthermore, loneliness has been associated with impaired cognitive performance and cognitive decline over time, increased risk of Alzheimer's disease and extending depressive symptoms (3).

Only by understanding loneliness, as experienced by the NH residents, strategies can be developed for support and relief. Therefore, this study aims to explore the feelings of NH residents, with a specific interest in feelings of loneliness.

Method

Study Design

This study is a qualitative, phenomenological, interview-based study, exploring feelings of loneliness in NH residents. In order to avoid residents to report loneliness as a consequence of it being the topic of the interviews, residents were interviewed on feelings they were struggling with in general. Afterwards, the focus was tightened to loneliness.

Setting and Sample

A convenience sample of four regional NHs (*name country*) with at least 60 residents were informed about the study by telephone. The study protocol was sent by e-mail. Three NHs confirmed their participation. All recruited NHs are acknowledged by the national health insurance agency (name).

NH residents were eligible for the study if they were aged at least 65, spoke Dutch, were admitted more than three months ago, and were able to participate in a 60-minute interview (Mini Mental State Examination (MMSE) $\geq$ 18 and no diagnosis of dementia). The responsible nurse screened the residents' mental state using the MMSE before the interview

began (12). Occupants in short-stay or assisted care facilities and palliative and aphasia patients were excluded.

Purposeful sampling was used to select rich and intense cases which enabled the researcher to explore in depth this study's central phenomenon of loneliness (13, 14). Nursing managers and staff nurses were involved in sampling in order to select NH residents who, in their opinion, seemed to struggle with their feelings. In this way we aimed to obtain full and rich personal accounts. The number of interviews was guided by the cross-case analysis and new participants were included until consensus across views was obtained.

A total of 11 residents living in three NHs in (region), (country) were included in this study. None of the selected potential participants refused to participate or dropped out. All interviews lasted between 30 and 90 minutes. The residents' characteristics are summarized in Table 1.

Data Collection

In-depth interviews were conducted by the first author (nurse researcher) from January to April 2015, in the residents' own rooms, with no others present, using an interview guide with open-ended questions. Before starting the interview, the researcher told the participants she was a nurse, conducting research on life in a NH as experienced by residents. General questions, such as 'how do you feel', were introduced first. If residents did not spontaneously talk about loneliness in the first 15 minutes, specific probes were asked (e.g. 'do you feel lonely in the NH?' and 'what does loneliness mean to you?'). Interviews were digitally recorded and transcribed verbatim. Field notes were taken immediately after the interview, to prevent the residents from being distracted.

The data from the interviews were supplemented with administrative data, data from the nursing chart and information from staff nurses (e.g. age, admission date, ADL-dependency, diagnosis of depression, remaining social environment).

Data Analysis

Data were analysed using Interpretative Phenomenological Analysis (IPA), a qualitative research approach, which is phenomenological in its focus on lived experiences with a particular significance for people, and idiographic because of its commitment to a detailed examination of the particular case. IPA offers detailed, nuanced analyses of particular instances of lived experience, and adopts analytic procedures for moving from single cases to more general statements. IPA acknowledges the researcher's conceptions and experiences, as brought to the analysis. IPA focusses on personal meaning and sense-making in a particular context, for people who share a particular experience, in this case our participants were all living in a NH and were all, according to the staff, struggling with their feelings (15). Data analysis followed the six-stage process described in detail in Smith, Flowers, and Larkin (2009) (15). As a first step, we read and re-read the transcript of the first interview to become familiar with the data. Initial notes were made (step two). In step three, we developed emergent themes at a higher level of abstraction from these initial notes. Then we searched for connections between themes and we plotted a diagram of the structure of these themes (step four). In step five, we moved on to the next case, repeating the previous four steps for every transcripts. Finally, in step six, we looked for patterns across cases. All the transcripts were analysed using the same procedure.

To ensure rigor, bracketing was practiced, using a reflexive journal, before starting the analysis and after step four, to enable the analyst 's focus to remain with the data (15). A second researcher (…, medical doctor and researcher) reviewed the analysis of the first transcript and the structure of the emergent themes across all transcripts to ensure that they

were clearly grounded in the data. In addition, the results were considered by two additional researchers (… and …, both registered nurses and scientists). To support reflexivity, the research team discussed the emergent themes and their connections. There was no previous relationship established with any of the participants prior to commencing the study.

Ethical Considerations

The Ethics Committee (EC) of … *(city, to be added after peer review)* University Hospital … *(country)* approved the study (EC-number 14/47/488).

The board of directors and the supervising general practitioner of the NH signed a study agreement and all residents signed an informed consent form.

Results

Loneliness

Participants seldom spontaneously started talking about loneliness. Only one informant spontaneously talked about feeling lonely. When specifically asked about loneliness, five other informants admitted being lonely. Generally, participants' descriptions of loneliness varied from aloneness to feeling unappreciated, boredom, not feeling at home in the NH and loss of autonomy and self-determination.

Interviewer: 'What does loneliness mean to you?'

'Loneliness? I don't know. Why am I feeling lonely? Because I 'm alone. I always say I'm all alone. I can't see. And I can't do anything. I can't do anything anymore. Because of my hand, I can't do anything with my hand. I wrote a postcard to someone yesterday, I wrote one word, and the second word… I started writing the second word over the first word… because I can't see properly. That's really annoying, you see.' (woman, 91 yrs, nh Z)

This extract draws attention to how loneliness can be related to physical decline and a loss of functional autonomy. This woman cannot participate in any activities organised by the NH

because of her physical deterioration. When questioned on participation in group activities, she said:

'No, I can't, you know, I'm not able to do anything. I don't attend, because I 'm not able to participate.'

Another informant admitted feeling very lonely, but found it very hard to describe what loneliness meant to him.

'The words fail me … Being alone… knowing nothing… being left out…' (man,74 yrs, nh X)

Both extracts related to a feeling of being left out and unappreciated.

Two others spoke of solitude as a positive feeling; they loved being alone. When questioned on her contacts with fellow residents, one woman explicitly said she did not want to socialize with her fellows. She had been living alone for many years before moving to the NH.

'No, I prefer being alone. All that chit-chat with other people, there's no need for that. I feel more at ease when I 'm alone.' (woman, 84 yrs, nh Y)

Feelings of loneliness were often caused by bereavement and a lack of family and friends. Visits from relatives, friends and other residents reduced loneliness. Being able to talk about their feelings with important others also brought some relief. However, when contacts with important others did not meet the participants' expectations, loneliness seemed to increase. This appeared to be related to the quality of the relationship with the visitor.

'A friend of mine is coming to visit, but only when he thinks about it. It's a long drive (to the NH)… but you are here too, aren't you? I expected him to come here more often. I don't want to force him to visit me more often.' (man, 77 yrs, nh Z)

Interviewer: 'What happens when he does visit you?'

'We talk about the past, mainly chit-chat. But I keep that short and snappy. And when he has had enough, he can say so, you know' (man, 77 yrs, nh Z)

‘I have a friend I really trust, I can tell him everything. I know him for 40 years and he still visits me. He supports me. He’s a very good person’ (woman, 91 yrs, nh Z)

Interviewer: ‘What is a good day for you?’

‘When someone visits me. My friend or my old neighbour, then I really feel happy’ (woman, 91 yrs, nh Z)

Both extracts draw attention to the quality of the relationship with the visitor, rather than the quantity of visits. The relationship with his friend does not meet the man’s expectations, neither the quantity of the visits, nor the quality of the conversations is satisfactory. The woman, however, is satisfied with the quality of the relationship.

For some, taking part in organized (group) activities made them feel less lonely, while others avoided contact with fellow-residents, mainly because of the perceived cognitive impairment of those others. Another reason to avoid participation with group activities was the need for individualized and personal care.

‘When I had just moved here, I ate with my fellow residents. I don’t do that anymore. I don’t want to sit with those people. No, I couldn’t sit with them. All that talking and, and, and, … they don’t know what they’re saying. I’d rather not be with them.’ (woman, 84 yrs, nh Y)

Instead of loneliness, at the start of the interviews, most participants clearly mentioned a significant loss of autonomy due to living in a NH, and grief caused by this and other loss (e.g. bereavement, loss of their home).

(Loss of) Autonomy

All participants felt their autonomy had been taken from them when they moved into the NH. Since the main reasons for their admission were physical decline and the growing need for formal care, these participants were already dependent on others for their activities of daily life (ADL) or their functional autonomy before being admitted to the NH. However, their growing dependence on others still bothered the participants a lot.

Apparently, losing their autonomy or self-determination bothered participants far more than loneliness and this loss seemed to coincide with the sense of leading a meaningless life, grief and mourning, feeling imprisoned, dejected and unappreciated, indignation, humiliation, melancholy, anger, fear and not feeling at home in the NH.

'Sometimes it's hard. Being washed by someone else and so on … I can't do anything myself. I can only wash my face and arms.' (woman, 92 yrs, nh Z)

'I want to be well taken care of. I'm incontinent and I'm totally wet when I wake up in the morning. So, they should help me to get out of bed early. If they forget, I have to go to breakfast all wet. Would you like that?' (woman, 92 yrs, nh Z)

'You have to ask for everything. Ask, ask, ask and wait, wait, wait.' (woman, 91 yrs, nh Z)

Study participants revealed two causes of their loss of autonomy, namely the need to ask healthcare workers for assistance and the obligation to wait a certain time for this professional help to arrive. In addition, some informants referred to being admitted to the NH against their wishes, while being questioned on their practical autonomy.

'I had to call the emergency number twice at home. And then my sister decided to put me in here (in the nursing home). I didn't have a say. She decided.' (woman, 92 yrs, nh Z)

Participants' reactions were either resistance or giving up. Resistance was often expressed by blaming healthcare workers or family members for their loss. However, feelings of aggression, sadness, frustration and/or humiliation were apparently present underneath and for some participants, expressing their feelings in an aggressive (angry) manner gave them strength.

'None of the staff ever visits me. They don't dare to approach me. One of them, shaking my hand, holding only my two fingers … that's not a handshake! It makes me feel so bad! It's like I have a contagious disease … and that's not true.' (woman, 91 yrs, nh Z)

Others seemed to have given up and resign to their current situation, apparently because they had no other option.

'There's nothing I can do about it… It is what it is.' (man, 77 yrs, nh Z)

Most informants expressed a strong desire to go back home or to get back to their old lives, but they appeared to realise this was not a realistic option. Although some participants expressed satisfaction with the care they received in the NH, others had a dismissive attitude towards living there.

'I want to live my life to the full. I want to do whatever I want to do, go outside and meet new people. I feel fine and I don't want to stay here (in the NH) any longer.' (man, 77 yrs, nh Z)

'I wish I felt better. That means everything to me. I wish I was young again and I could go back to school. I miss my job. I loved the children in my class and they loved me back. In here they don't love me.' (woman, 91 yrs, nh Z)

Both extracts draw attention to the loss of autonomy due to physical deterioration and increasing dependence on others, which is also related to a loss of freedom from the man's point of view. Both informants strongly express a desire to go back to their old lives, outside the institution, and a need to feel appreciated.

Grief

Feelings of grief were present in all the interviews, often coinciding with the loss of autonomy as well as mourning about the loss of their partner, family and friends and their home. Not surprisingly, most informants found it hard to talk about their loss and tended to become very emotional about these issues. Also questions about future prospects and the meaning of life seemed to be difficult to answer and were sometimes avoided by participants by changing the subject.

'Losing my husband and my home hit me really hard. I was deeply depressed for a whole year after

selling my house… My husband always said I should never leave our home, but I couldn't stay there anymore because of the falls… I still miss my husband, every day.' (woman, 91 yrs, nh Z)

Discussion

Loneliness was not the most prominent feeling for the informants of this study. When questioned on their general feelings at the start of the interview, only one informant spontaneously answered he felt lonely. Other feelings appeared to be more crucial, such as feelings coinciding with a loss of autonomy and grief.

Loneliness

Participants' loneliness was all about the perceived quality of their relationships with important others, and an unfulfilled need for meaningful relationships. Feelings of loneliness had little to do with the number of contacts, getting regular visits or participating in group activities, although these aspects seemed to reduce loneliness. Apparently, contacts with fellow residents and health care professionals in the NH were perceived as not being meaningful, and some contacts with visitors were disappointing.

Loneliness was strongly associated with loss of self-determination or autonomy due to institutionalisation and with feelings of grief. This is consistent with the findings of Larsson, Rämgård, and Bolmsjö (2017) which describe that older persons experience (existential) loneliness when they are increasingly limited in body and space due to an increased dependency on others (16).

Meaningful relationships

When considering a broader definition of loneliness, transcending social loneliness and including emotional and existential loneliness, many of the feelings reported by the participants can be understood as loneliness. Besides a consequence of social contacts, loneliness was often caused by a lack of meaningful relationships, in which informants could

talk about their feelings. Relationships with important others who did not meet participants' expectations, increased loneliness. This relates to the emotional dimension of loneliness, and is consistent with the findings of Routasalo, Savikko, Tilvis, Strandberg, and Pitkälä (2006) on the association between emotional loneliness and residents' expectations and satisfaction of contacts with family and friends (17).

Relationships with fellow residents and staff

The available contacts with fellow residents and staff do not fulfil the residents' need for meaningful relationships. Moreover, when it comes to establishing new relationships in the NH, our study implies that residents avoid contact with fellow residents because of their perceived fellows' cognitive impairment. This is similar to a study of Lee, Simpson and Frogatt (2013), highlighting the extent of older adults' fear of losing their memory: participants in this study distanced themselves from other residents based on their abilities, specifically in relation to memory (18). With respect to group activities, events organized by the NH give residents the feeling of belonging to a group, which also seemed to reduce loneliness for some participants in our study (19-21).

The meaning of life

Most participants found it hard to talk about their feelings and tended to get very emotional during the interview. Questions about their future and the meaning of life were difficult to answer, although some participants referred to living in a NH as 'leading a meaningless life', which might relate to an existential dimension of loneliness.

Feelings of emotional or existential loneliness were expressed, yet not considered to be loneliness by the informants themselves, who spontaneously talked about their feelings coinciding with a loss of autonomy.

Self-determination and autonomy

Our results seem to acknowledge that self-determination or autonomy is connected to leading a good life from the residents' perspective, a conclusion which was also made in a recent study by Bollig, Gjengedal and Rosland (2016) (22). Consistent with the findings of a qualitative study identifying autonomy or self-determination and meaningful (individualized) activities as two out of ten central dimensions of residents' quality of life, participants in our study also expressed their need for individualized, personal care and meaningful relationships (21). Furthermore, a systematic literature review identified preservation of autonomy as one of three key factors that impact mentally fit residents' transition and adjustment to NH care (23). Nevertheless, moving from home to a NH is more than just a physical move or a change of address. It influences the older adults' identity, their sense of belonging and their wellbeing (23). In our study, losing their autonomy seemed to coincide with strong feelings of e.g. grief, indignation, humiliation, anger and not feeling at home in the NH. This is consistent with the findings of Johnson and Bibbo (2014), which indicate losing their autonomy hampers residents' willingness to assign the label "home" to the NH. Personal adjustment appears to be connected with a degree of autonomy within the limits of life in an institution (24).

Strenghts and limitations

To the best of our knowledge, this is the first study to describe the perception of NH residents on the meaning of loneliness. To ensure in-depth data collection, residents were interviewed face-to-face, using open-ended questions. Interviewing them in their own private room may have created an open atmosphere, enabling them to talk about positive as well as negative experiences. IPA allows for a detailed examination of particular instances of lived experience, which can lead to a significant contribution to psychology. It involves a double hermeneutic: the researcher is making sense of the participant making sense of what is happening to them, thus IPA analysis always involves interpretation. It is important for the

readers to note that interpretations are presented as possible readings, and that they are positioned as attempting to make sense of the researcher trying to make sense of the participant's experience (15).

Certain limitations of our study need to be acknowledged. Firstly, the participants appeared to be more reserved in the initial interviews and, although we changed our approach into a more general one that encouraged the residents to talk more openly, it continued to be difficult for them to talk about 'loneliness'. This is possibly due to a social stigma or negative connotation connected with loneliness and it may also be partly cultural determined. In addition, two interviews in the first series lacked depth because of participants' evasive answers to some of the key questions, so the results are mainly based on nine interviews, which decreased the variety of the sample of residents included. However, sampling consistent with IPA's orientation towards getting an insight into a particular experience means that samples are preferably small and fairly homogenous. Smith et al. (2009) suggest that between three and six participants can be a reasonable sample size and should provide sufficient cases for the development of meaningful points of similarity and difference between participants (15). Secondly, as a result of this general approach, data on loneliness were rather limited, because other feelings seemed to be more prominent to our informants. However, our strategy provided rich data on loneliness and more crucial feelings, such as feelings coinciding with a loss of autonomy. Moreover, the finding that loneliness was not the most prominent feeling in this sample of NH residents who seemed to be struggling with their feelings is an important and relatively new finding. Next, the specific context of NHs in (region) may limit the transferability of our results, although some parallels with international studies have been established. Finally, we found a lot of negative perceptions about NHs in our study population. Our focus on participants who appeared to feel lonely or struggle with (negative) feelings might have contributed to the rather negative image of the NH and its

staff. Other research confirms that having a positive attitude towards living in a NH increases acceptance and adaption (25).

It is important to note that loss of autonomy coincided with feelings of grief. However, no earlier studies were found focusing on this association in nursing home residents.

Implications for Practice

Interventions focusing on meaningful relationships, meaningful life and self-determination or autonomy are needed. Healthcare professionals should talk about the nature and content of these interventions with the resident and his family and make time to explore residents' preferences in depth.

Loneliness

Healthcare professionals should more proactively screen for loneliness to facilitate early identification of such feelings (8). It is crucial to identify those residents who are at risk of being lonely and to create appropriate interventions focused on the maintenance and enhancement of social networks to reduce older adults' loneliness (19-21).

Meaningful relationships

By stimulating new and meaningful relationships with fellow residents and staff, and by providing opportunities for their residents to talk about their feelings and life experiences, loneliness may be prevented (23, 26).

Self-determination and autonomy

Our research shows that autonomy or self-determination could be an important predictor for loneliness. However, many of the routines currently used in NHs leave little room for negotiation or individualized, personal care. Existing research has also shown that giving some control to the residents has a positive influence on their wellbeing (7). Therefore,

healthcare workers should be aware of the importance of autonomy for their residents and the feelings and needs this evokes (e.g. grief), in order to provide a good quality of care (27, 28).

Recently, advances are made in implementing interventions targeting autonomy and emotional well-being among frail older people in NHs, such as interventions based on peer support, active ageing, and person-centred care (26, 29, 30).

Nursing training programs and other health care education programs should focus on strategies to improve residents' quality of life, emphasizing the importance of meaningful relationships, leading a meaningful life and preservation of autonomy for the residents.

Conclusion

Loneliness is more than being alone among others. The unfulfilled need for meaningful relationships plays a crucial role in feelings of loneliness. Losing their self-determination due to institutionalisation causes strong emotions, such as grief. It is vital that health care professionals are aware of these feelings and pay more attention to resident preferences while developing (individualized) interventions to prevent loneliness. Interestingly, participants did not spontaneously and explicitly talk about 'feeling lonely', while examples given indicate otherwise. The dimensions of loneliness identified in our study are emotional and social loneliness. The existential dimension of loneliness was difficult to identify. Further research is necessary to confirm and extend our results regarding the association between autonomy, grief and feelings of loneliness, and to probe further into this underlying existential dimension.

List of abbreviations

NH: nursing home

MMSE: Mini Mental State Examination

IPA: Interpretative Phenomenological Analysis

Ethics approval

Competing interests

The authors report no conflict of interest.

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Authors' contributions

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